

Attitudes, knowledge and beliefs about dementia: focus group discussions with Pakistani adults in Karachi and Lahore

Article (Accepted Version)

Farina, Nicolas, Zaidi, Asghar, Willis, Rosalind and Balouch, Sara (2019) Attitudes, knowledge and beliefs about dementia: focus group discussions with Pakistani adults in Karachi and Lahore. Ageing and Society. ISSN 0144-686X

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Attitudes, Knowledge and Beliefs about Dementia: Focus Group Discussions with Pakistani Adults
in Karachi and Lahore.

This is the Accepted Manuscript for the following article: Farina, N., Zaidi, A., Willis, R., & Balouch, S. (2019) Attitudes, Knowledge and Beliefs about Dementia: Focus Group Discussions with Pakistani Adults in Karachi and Lahore. *Ageing and Society*

Abstract

Pakistan is a lower middle-income country, which to date has had very little research and policy making to address the challenge of dementia. This study aims to explore the perceptions of dementia in a group of Pakistani adults. A series of Focus Group Discussions were completed during 2017 with men and women in two metropolitan centres in Pakistan (Lahore and Karachi) (n=40). Two vignettes, depicting someone with mild dementia and someone with severe dementia, were used to facilitate discussions. An induction led thematic analysis was completed. Five themes were identified, reflecting (i) dementia awareness, (ii) responsibility, (iii) barriers to healthcare, (iv) identified support needs, and (v) religion. Most participants had little awareness and knowledge about dementia, commonly understood to be a disease of forgetting or just normal aging. Thus, there is an urgent need of a nation-wide campaign to raise dementia awareness in Pakistan, though this needs to be accompanied by improved, accessible health and social care services.

Keywords: awareness, stigma, cognitive impairment, lower-middle income, religion

Introduction

Very little known is about the exact prevalence of dementia in Pakistan (Hussain *et al.* 2017). Low and Middle-Income Countries (LMICs), which includes Pakistan, are projected to show the greatest increase in dementia prevalence in over the coming decades (Prince *et al.* 2015), largely driven by the rapid increase of life expectancies. However, this is only part of a more complex picture of dementia in LMICs. For example, people within LMICs such as Pakistan, are more susceptible to cardiovascular disease and diabetes (Misra *et al.* 2017), which subsequently is associated with increased risk of dementia (Kloppenborg *et al.* 2008; Whitmer *et al.* 2005). Furthermore, under-resourced education systems mean that many LMIC populations tend to be poorly educated, which also is a risk factor of dementia (Livingston *et al.* 2017).

Pakistan is currently the sixth most populous country in the world with an estimated older population of 12.5 million in 2017. In percentage terms, older people constitute only about 6.5 per cent to 7 per cent of the total population, but they are by no means an insignificant segment of the population in terms of their number now. Pakistan belongs to a group of only 15 countries worldwide that have more than 10 million older people. In the future, the rising life expectancy will lead to an increasing number of old and very old people in Pakistan. By 2050, the number of older persons living in Pakistan will reach a staggering 40 million (Zaidi *et al.* 2018: 2). Pakistan ranks extremely low in the Global AgeWatch Index, at 92 out of 94 countries, which measures well-being of older populations using multidimensional indicators. The country ranks particularly low with respect to health of older persons, with a relatively low life expectancy and even lower healthy life expectancy within the region (Zaidi 2013). Despite the rising number of older people in Pakistan and their low socio-economic status, there is very little research on issues linked with old age and dementia (Khan 2014). Greater bodies of dementia literature exist in countries geographically close to Pakistan (i.e. India), however, it is difficult to make inferences due to Pakistan's unique

historical, cultural and political background. There is currently no government policy in Pakistan to provide specialist health care for people living with dementia, relying instead on family caregivers playing a central role (Zaidi *et al.* 2019).

Within LMICs such as India, features of dementia appear to be widely recognised (Cohen 1995; Patel and Prince 2001). Despite this, dementia is often incorrectly considered to be part of normal aging, or there are stigmatising beliefs about dementia more broadly (Ferri and Jacob 2017; Li *et al.* 2011; Maestre 2012; Patel and Prince 2001). Lack of awareness and stigma of dementia can lead to people not seeking a diagnosis, support, treatment or information about dementia (Alzheimer's Society 2008; Iliffe *et al.* 2005; Milne 2010). Therefore, raising awareness of dementia is a worldwide priority, as set out in World Health Organisation's Global action plan on dementia (World Health Organisation 2017b), in part because raising awareness is a key pathway to enhance timely diagnosis and reduce stigma (Mukadam and Livingston 2012). However, before this can be initiated, it is important to establish what people's attitudes, beliefs and knowledge currently are in LMICs, whilst being aware that they will be country and culturally specific. To date, there is limited data originating from Pakistan. One study, carried out more than five years ago, has explored such perceptions in Pakistan, albeit from the perspective carers of people with dementia. In the study, carers were found to have a limited awareness of dementia despite their caring role, and that they often believed it was caused as a part of normal ageing process or secondary to traumatic events or stressors (Qadir *et al.* 2013). Similar findings have been found in Pakistani communities living abroad (Nielsen and Waldemar 2016).

The aim of this study is therefore to explore perceptions of dementia, its treatment and care in a small group of adult Pakistanis residing in two urban centres.

Methods

Design

Focus group discussions (FGDs) were used to facilitate interactions and are recommended for use to explore the beliefs about health and disease (Bowling 2014). Vignettes were used during the FGDs as a means to depersonalise the content, and therefore better allow participants to express their views on a sensitive topics (Barter and Renold 1999; Schoenberg and Ravdal 2000).

Participants

A total of 40 participants (20 male and 20 female) were recruited across two sites in Karachi and Lahore, Pakistan. Situated in the provinces of Sindh and Punjab, respectively, sites were selected because they represent the two most populous cities in Pakistan. Potential participants were identified through word of mouth, through local community groups and existing contacts. Participants were selected to maximise heterogeneity in the sample. Participants were excluded if they were currently caring for someone with dementia, as the aim was to explore perceptions of people who had no personal experience of dementia. There was no upper restriction on the age of the participant. All participants were required to be Pakistani and speak Urdu.

Procedure

Each FGD was composed of 10 same-sex participants. All participants were provided an information sheet and informed consent was obtained. The facilitator began each session by introducing the FGD and describing the purpose of the research, after which a series of ground rules were set. The participants were then asked to introduce themselves and were then verbally presented the first of two vignettes. In addition, the vignettes, written in Urdu, were made available

on paper to those that were literate. Participants were then asked a series of semi-structured questions by a facilitator regarding each vignette. For example:

- What do you think is happening to *[the person]* in the story?
- How do you think *[the person]*'s family feels about her problems?
- What do you think *[the person]*'s family should do about it?

Following the discussion of each vignette, the facilitator asked a series of semi-structured questions about dementia more broadly. For example:

- What is dementia?
- What is the cause of dementia?
- Who do you think should be responsible for looking after people with dementia?

After the completion of the FGD, participants were asked to complete a series of questions about their demographics, alongside their previous contact with dementia. Researchers read these questions and supported their completion.

All study materials and discussions were in Urdu, which were subsequently translated to English. The FGDs were completed in August 2017.

Two separate research teams ran the FGDs, one in Lahore and one in Karachi.

- 1) The Karachi FGDs were led by a female facilitator. The Karachi facilitator was Pakistani born, and was fluent in Urdu, Sindi, English and Balochi. Two additional researchers, one male, one female, who were also Pakistani born, took notes, and provided additional support when needed. The Karachi FGDs were held in a community setting in Korangi, Karachi.
- 2) The Lahore FGDs were led by a female facilitator. The Lahore facilitator was Pakistani born, and was fluent in Urdu, Punjabi and English. Two additional researchers, both males,

were present as observers during the discussion. The Lahore FGDs were held in the offices of Alzheimer's Pakistan.

Measures

Demographic information was collected from participants, including age, gender, level of education and measures of socio-economic status. In addition, participants were asked to complete a series of questions about their experiences of dementia, which was a translated and adapted version of an existing dementia level of contact questionnaire (Farina *et al.* 2019).

Vignettes

Two vignettes were created, one describing someone with mild dementia and the other with severe dementia (See Figure 1 for the example). The vignettes were adapted from those previously used in a study exploring awareness of dementia in UK minority ethnic groups (La Fontaine *et al.* 2007).

La Fontaine and colleagues originally created the vignettes to reflect both the language and experiences from previous FGDs whilst utilising symptoms that fit with diagnostic criteria of dementia. In the present study, the two vignettes were further adapted to ensure that they were appropriate for a Pakistani population. In line with common practice, the vignettes were rewritten in the third person and ages of the cases were added (Randhawa *et al.* 2015). Specifically, the vignettes used refer to two hypothetical cases of Mrs Shabnam and Mrs Gulnara, both 72 years old. The vignettes were reviewed by British dementia-related researchers, British dementia-related healthcare staff, and Pakistani academics and clinicians to ensure that the descriptions were believable and accurately reflect symptoms of dementia and its severity. The vignettes were then translated into Urdu and reviewed by a Patient and Public Involvement Group in Pakistan, who provided further input into the vignettes. The final versions were then independently reviewed by a bilingual researcher to ensure that the translated versions maintained their meaning.

[Insert Figure 1 about here]

Analysis

Demographic information and previous experience of dementia were reported descriptively (e.g., frequencies).

All audio recordings were transcribed in Urdu initially and then translated into English by multilingual researchers in Pakistan. A thematic analysis using inductive approaches was carried out, taking an interpretivist epistemological position. The lead British author of this paper used an open-coding approach to code a single FGD transcript, utilising phrasing as close as possible to participants' own words. This was then independently reviewed by three researchers (1 British, 1 Irish and 1 Pakistani) who added and commented on the emerging coding framework; disagreements were resolved through discussion amongst the researchers. The lead author then continued to code the remaining transcripts, adding new codes when identified. Codes reflecting connected concepts were then grouped into higher order sub-themes and themes.

Ethics and Rigour

Informed consent was obtained from all participants. For participants who were illiterate, the information sheet, consent forms and vignettes were read out to them.

To ensure that the Urdu transcriptions were translated accurately, without losing the original meaning, translations were completed by the multilingual research team who led the FGDs. We attempted to keep the wording as close to the direct translation where possible, but sometimes the wording was altered to ensure that it made grammatical sense. In some situations the choice of wording is pertinent to understanding the context; this has remained unchanged but is expanded within brackets.

A single FGD from each site was independently observed by a researcher (NF or AZ) to make notes on FGD procedure and to provide additional rigour. During the coding, the researcher (NF) met with an independent researcher to discuss coding themes and to support the process of reflexivity. NF was able to reflect upon his own position as a researcher within the UK and how this might affect the interpretation of findings. The final coding and formation of themes were discussed amongst members of the research team and broader scientific advisory board (composed of Pakistani clinicians and academics) to ensure the findings remained valid.

Results

Across all sites, 40 participants completed the FGDs. On average participants were 37.2 years old, lived in a household of 6.5 people and most commonly had been educated to A level or equivalent Faculty of Science (FSc) standard (n=9). See Table 1 for further details of the demographics of each site. The majority of participants had never encountered someone with dementia (n=30, 81.1%), spoken to family or friends about dementia (n=27, 73.0%), been taught about dementia in school (n=35, 94.6%) or watched a TV shows or movies in which a character has dementia (n=24, 64.9%).

[Insert Table 1 about here]

From the FGDs, five key themes were identified: 1) Dementia awareness, 2) Responsibility, 3) Religion, 4) Barriers to healthcare, and 5) Identified support needs.

Dementia awareness

Participants tended to have very little knowledge of dementia, identifying a variety of causes for the symptoms described in the vignettes. Most prominently, participants felt that the symptoms described in both vignettes were due to normal age-related decline.

“Commonly, this is because of old age that it is an ailment.”

Female, Karachi (FK1)

Second to normal age-related decline, many participants also incorrectly identified that the cause of dementia was due to life-stresses, often referred to as ‘tension’.

“...because of the ‘tension’, the person has the disease of forgetting [dementia].”

Female, Karachi (FK7)

“It [dementia] happens because of worries.”

Male, Karachi (MK6)

There were a few participants that did understand that the vignettes were about dementia, or more commonly recognised it as being related to ‘forgetfulness’. It is also important to highlight that participants were correctly able to recognise that a diagnosis of diabetes (as described in the first vignette) might be associated with dementia.

“...one thing that I noticed is that the forgetting issue is somehow being related to diabetes”

Male, Lahore (ML1)

Irrespective of the cause, misconceptions led to some participants holding incorrect views of prognosis and the treatment for those with dementia. A subgroup of participants believed that symptoms might improve, or the disease is curable.

“...if her household and herself takes a little more care...Then her ailment will disappear.”

Male, Karachi (MK6)

Responsibility

Responsibility featured heavily throughout the FGDs, with participants commonly identifying that the responsibility of accessing or providing dementia care lies with either the person with dementia or their family. The perception that it was the family's responsibility to provide care was driven, in part, by societal norms. This sometimes led to an emphasis of children taking a greater responsibility compared to other family members.

“It is the responsibility of the children to look after their mother and father. God has given us the courage; it is our right (privilege) that we should take care [of them].”

Female, Karachi (FK6)

Tied with this, participants saw that the cases described in the vignettes as being the fault of the families because they did not give enough time or attention.

Participants in the FGDs also identified that there was an element of personal responsibility when it came to dementia and its symptoms. More interestingly, some felt that the individual acted as a barrier (e.g. lazy or apathetic) to their own healthcare.

“In my view Shabnam herself was hurdle for her treatment, because she had stopped meeting relatives. She has become fed-up. (So) she was herself a hurdle and nothing else.”

Male, Karachi (MK6)

As such, it was seen that the person with dementia is partially, or wholly responsible for their own care or treatment.

“In my opinion she [Shabnam] should remove these barriers herself.”

Male, Karachi (MK7)

“Mrs. Shabnam should herself take steps; she can bring herself back with her own will power. She should take steps herself and household members should also push her.”

Female, Karachi (FK8)

Religion

Closely related to responsibility, religion was also used to provide context into why the family members should provide care for someone with dementia, often in very certain terms. Participants usually rationalised that it was the children’s duty to care for their parents, often citing religious texts.

“It is very clearly mentioned in the Holy Quran that you need to treat your parent like your parents treated you when they were young. And you are not allowed to be mad at them, you can’t even utter a single word in anger. From this saying we get the lesson that we should take care of them and never leave them at any stage. We should always give them attention and we shouldn’t neglect them. We shouldn’t ignore them. This is the basic religious lesson.”

Female, Lahore (FL1)

“If you follow religion, then you cannot leave your parents until the end. If you are religious, then you should remain loyal (to your parents) until the end.”

Male, Karachi (MK1)

Religion was also used as a means of describing how best to treat dementia as well as to inform its prognosis. However, participants tended not to provide reference to religious texts or teachings when describing these opinions. A common theme, particularly amongst the Karachi FGDs, was that prayer could be a means of preventing or treating dementia.

“Whoever keeps Allah pleased then, everybody is pleased. If we perform Farz¹ then, it is my conviction that we all can remain safe from disease. Everybody should pray (and follow their religious values).”

Female, Karachi (FK3)

“If we remember Allah then we can remain safe from all the diseases.”

Female, Karachi (FK5)

Barriers to healthcare

Participants often struggled to identify potential barriers to accessing care for someone living with dementia, aside from self- or family-related barriers (see above). However, finances were occasionally identified as a key barrier to accessing support and healthcare.

“Household members would like to (medically) treat her, but they don’t have the money...”

¹ Farz or farīdah is an Islamic term which denotes a religious duty commanded by Allah (God).

Male, Karachi (MK1)

Some of the participants also felt that the current healthcare system was a barrier to receiving care. Either because of feelings that the doctors were not sufficiently trained, that they did not have the patients best intentions at heart, or that they would make an incorrect diagnosis.

“If I take them to a government hospital, then the doctor will tell me that their symptoms are due to old age, therefore I should take care of them and pray for them.”

Female, Lahore (FL2)

A smaller group of participants identified that stigma may act as a barrier; either from the stigma derived from receiving a formal diagnosis or the fact that getting external help was seen as a failure on the part of the family.

“That if we will send our parents to day care then what will other people say about us? If we will hire some helper then what will the people think or say about us?”

Female, Lahore (FL2)

It was only within perceived barriers where the gender of participants appeared to influence responses. Female participants were more likely to highlight that the family dynamics could act as a barrier, with views of certain family members being prioritised over others. For example, it was felt that if the daughter identified a need for additional support this could be overridden by the son.

Identified support needs

Despite individuals' limited knowledge of dementia, participants identified that more that could be done for people with dementia in Pakistan. Most frequently, participants identified the need to raise more awareness about dementia. A portion of participants suggested that TV and radio was the best means of raising awareness, though others felt that using a strategy similar to those used to raise awareness of Polio and Dengue Fever (discussed in next section) would be more effective. Whilst participants did not often raise the view that the government should be responsible for dementia care, it was seen as being primarily responsible for raising awareness.

Participants believed that new facilities (e.g. hospitals) and specialists were needed, though this was predicated with the notion that any facilities opened should be accessible, low-cost and relaxing (i.e. not stressful). Most importantly, it was seen that any new facilities and services should be accompanied with information about how and where to access this healthcare.

“Institutions should be opened immediately and the ones that are open, should provide environment akin to home.”

Male, Karachi (MK2)

Discussion

The purpose of this study was to explore the perceptions of dementia amongst a series of focus groups of Pakistani adults. Through the use of vignettes and FGDs, we were able to identify five key themes that summarised their perceptions of dementia.

The FGDs highlight that there is often lack of knowledge and awareness of dementia amongst the Pakistani adults, leading to incorrectly identifying the cause of symptoms, dementia's prognosis and how best to treat it. In line with previous literature from other LMICs, the common view was that dementia is a normal part of ageing (Ferri and Jacob 2017; Li *et al.* 2011; Patel and Prince 2001).

This is perhaps unsurprising considering the majority of participants had no experience of dementia during their education or throughout their lives. Lack of awareness of dementia is likely to act a barrier to accessing support services in the future, with greater knowledge of dementia being associated with increased intention to seek help (Werner 2003). Perhaps more concerning is that fact that some participants associated dementia symptoms with being the fault of the individual (e.g. they are their own hurdle) or family, which is potentially stigmatising. This could explain, in part, why there appears to be little dialogue and research about dementia.

It should be noted that there did appear to be knowledge or recognition of dementia from a subgroup of participants within the study, with participants correctly referring to dementia as a disease of “forgetting”. This may not be surprising because previous qualitative evidence from India has showed that the features of dementia are generally widely recognised (Cohen 1995; Patel and Prince 2001). Similarly, the term “disease of forgetting” has specifically been used within other LMICs such as Tanzania to describe dementia (Mushi *et al.* 2014). Obviously, forgetfulness does not fully capture what dementia is, but recognition of symptoms is important. Participants’ ability to draw links between dementia symptoms and diabetes may be indicative of some recognition or implicit knowledge of dementia risk factors (Kloppenborg *et al.* 2008; Ott *et al.* 1999).

Raising dementia awareness was seen as a priority by participants. TV and radio were seen as the best way to reach the majority of people, whilst many felt that the use of awareness campaigns similar to those for Polio or Dengue Fever would be beneficial. In the case of Polio, a mass media campaign and targeted community engagement was used to raise awareness (National Emergency Operation Centre 2017), but this was complemented with support from international leading Islamic scholars (World Health Organisation 2014). It has previously been commented that Islamic institutions play an important role in promoting mental health, through routes such as public information and health education (Baasher 2001).

Even in this sample of Pakistanis, with little knowledge or awareness of dementia, participants were able to identify barriers to accessing healthcare, such as financial restrictions. Whilst wealthier Pakistanis may have private healthcare insurance, out-of-pocket payments are the largest source of private expenditure for healthcare (65%, 2014) (World Health Organisation 2017a). Even government facilities that are officially free of charge may result in individuals giving unofficial payments or bribes due them being over utilised and under resourced (Malik 2015).

96.3 per cent of Pakistanis are Muslim (Pakistan Bureau of Statistics 2019), therefore, it is unsurprising that religious beliefs were used as a means to provide a direction in relation to dementia care. Notably, the family (in particular adult children) were seen as being responsible for providing such care, which was tied in with the teachings of the Quran *“And your Lord has decreed that you worship none but Him. And that you be dutiful to your parents. If one of them or both of them attain old age in your life, say not to them a word of disrespect, nor shout at them but address them in terms of honour.”* (Quran 7:23, Muhsin Khan Translation). As supported by evidence from South Asian family carers in the UK (Mackenzie 2006), religious obligation, and the associated stigma associated with seeking help, is therefore likely to lead to family carers to become isolated. This is not to say that the views from the FGDs fully capture the complexities in theological interpretations of dementia care within Islam, and it may be that the group setting led participants to avoid conflict and share more socially accepted, normative opinions (Smithson 2008). Irrespective, it is evident that an individual’s understanding of Islam plays an important role in shaping opinions about dementia. This can be observed in people with a diagnosis of dementia in Pakistan, with some being unclear about the religious obligations of those with dementia (Willis *et al.* 2018). Future research using individual interviews may assist in delving deeper into this complex topic.

There are a number of key strengths of this study. First, the FGDs were composed of participants with a range of education levels, ages, and household incomes. The heterogeneity within the FGDs, maximises the variability in opinions from these metropolitan areas. Recruiting from two urban centres, also reduces the likelihood that the sample reflects the opinions and views of a single region. Second, the FGDs were organised to be homogenous within each group in terms of gender (i.e. single-sex). Creating groups with more homogenous characteristics not only facilitates productive group discussions, but also makes it easier for comparisons to be made between groups based on a single characteristic (Hennink 2007; Krueger and Casey 2014). In particular, gender has previously been identified as being an important characteristic to consider, with the gender composition of a focus group effecting the nature of the interaction (Krueger and Casey 2014; Stewart and Shamdasani 2014), with females in mixed-sex focus groups tending to be less dominant. Finally, the use of vignettes allowed for participants to discuss a potentially difficult topic by depersonalising it (Barter and Renold 1999; Schoenberg and Ravdal 2000). It also meant that all participants received the same description of symptoms associated with dementia, which provide a standardised context to discuss the topic.

The study did, however, have several limitations. The findings reflect the views of a small group of adults from Pakistan. Every effort was made to encourage participation from people with a range of social and economic backgrounds. However, as recruitment was through word of mouth, and the results are derived from a small group, the views are unlikely to fully reflect the views of all 207 million Pakistanis. Importantly, participants were primarily recruited from two metropolitan centres (Lahore and Karachi), and therefore may not capture the views from Pakistanis residing in more deprived, rural areas. It is also possible that certain demographics may have chosen to not participate in the FGDs because of their views on the topic, or the setting in which the FGDs were run. For example, in the present sample, 85 per cent of participants achieved over a primary level of education, which is likely to reflect a more educated Pakistani population considering the Gross

Enrolment Rate alone to primary schools (2016-2017) was 87 per cent (Government of Pakistan 2017). As highlighted above, the FGDs may also not fully reflect more extreme views due to group settings encouraging more socially accepted opinions to be shared (Smithson 2008). As such, distributing an anonymous survey of dementia attitudes and knowledge may be a logical next step to provide more generalisable evidence, whilst also being in a format that would be less susceptible to reporting socially acceptable opinions.

This is the first study to explore, in-depth, the perceptions of dementia in Pakistani adults who have had no specific contact with people with dementia. Although the findings only reflect a small sample of adults residing in urban centres, it provides a unique insight into common misconceptions about dementia and also areas in which to help individuals to access support. This study is an important first step in the advocacy for dementia care reform in Pakistan. It is evident that raising awareness about dementia is essential; however, this needs to be accompanied by improved specialised dementia healthcare services. The role of religion obviously plays an important role in shaping attitudes within Pakistan, and therefore future efforts should explore how best to shape the narrative surrounding dementia in Islam.

Ethics

The University of Southampton and Aga Khan University ethics committees approved this study.

Acknowledgements

A special thank you to all the participants that took part in the research, and the user involvement in Pakistan (Alzheimer's Pakistan). We also wish to thank our project partners in Pakistan, particularly Hussain Jafri of Alzheimer's Pakistan for the data collection in Lahore, and Qurat Khan of the Aga Khan University, and Rubina Jaffri and Irfan Ahmed of HANDS for the data collection in Karachi, without whom this project could not have taken place. We are grateful for the encouragement and

support from Chris Roles (Chief Executive Officer of Age International) and Yasmin Rashid (Minister of Punjab for Primary and Secondary Healthcare, and Specialised Healthcare and Medical Education). We are grateful for the contribution of Laura J Hughes who acted as an independent consultant during the research.

Funding

This research was funded by Age International, Age UK, and HelpAge International.

Conflicts of interest

None to declare

Author contributions

N Farina wrote the first draft of the paper, helped plan the study, performed the analyses, and revised the paper. A Zaidi, R Willis and S Balouch helped plan the study, revised the paper, and contributed to the analysis.

References

- Alzheimer's Society (2008). *Dementia: out of the shadows*. Alzheimer's Society, London, England.
- Baasher, T. A. (2001). Islam and mental health. *Eastern Mediterranean Health Journal*, **7**, 372–76.
- Barter, C. and Renold, E. (1999). The use of vignettes in qualitative research. *Social research update*, **25**, 1–6.
- Bowling, A. (2014). *Research methods in health: investigating health and health services*. McGraw-Hill Education (UK).
- Cohen, L. (1995). Toward an anthropology of senility: anger, weakness, and Alzheimer's in Banaras, India. *Medical Anthropology Quarterly*, **9**, 314–34.
- Farina, N., Hughes, L. J., Griffiths, A. W. and Parveen, S. (2019). Adolescents' experiences and perceptions of dementia. *Aging & Mental Health*, **0**, 1–7.
- Ferri, C. P. and Jacob, K. S. (2017). Dementia in low-income and middle-income countries: Different realities mandate tailored solutions. *PLOS Medicine*, **14**, e1002271.
- Government of Pakistan (2017). *Pakistan Economic Survey 2016-2017*. Government of Pakistan, Islamabad, Pakistan.
- Hennink, M. M. (2007). *International focus group research: A handbook for the health and social sciences*. Cambridge University Press.
- Hussain, G., Rasul, A., Anwar, H., Sohail, M. U., Kamran, S. K. S., Baig, S. M., Shabbir, A. and Iqbal, Javed (2017). *Epidemiological Data of Neurological Disorders in Pakistan and*

Neighboring Countries: A Review. *Pakistan Journal of Neurological Sciences (PJNS)*, **12**, 52–70.

Iliffe, S., De Lepeleire, J., Van Hout, H., Kenny, G., Lewis, A., Vernooij-Dassen, M. and DIADEM Group (2005). Understanding obstacles to the recognition of and response to dementia in different European countries: a modified focus group approach using multinational, multi-disciplinary expert groups. *Aging & Mental Health*, **9**, 1–6.

Khan, Q. (2014). Dementia: Challenges of practice in Pakistan. *Neurology*, **83**, 2091–92.

Kloppenborg, R. P., van den Berg, E., Kappelle, L. J. and Biessels, G. J. (2008). Diabetes and other vascular risk factors for dementia: Which factor matters most? A systematic review. *European Journal of Pharmacology*, **585**, 97–108.

Krueger, R. A. and Casey, M. A. (2014). *Focus groups: A practical guide for applied research*. Sage publications.

La Fontaine, J., Ahuja, J., Bradbury, N. M., Phillips, S. and Oyeboode, J. R. (2007). Understanding dementia amongst people in minority ethnic and cultural groups. *Journal of Advanced Nursing*, **60**, 605–14.

Li, X., Fang, W., Su, N., Liu, Y., Xiao, S. and Xiao, Z. (2011). Survey in Shanghai communities: the public awareness of and attitude towards dementia. *Psychogeriatrics: The Official Journal of the Japanese Psychogeriatric Society*, **11**, 83–89.

Livingston, G., Sommerlad, A., Orgeta, V., Costafreda, S. G., Huntley, J., Ames, D., Ballard, C., Banerjee, S., Burns, A., Cohen-Mansfield, J., Cooper, C., Fox, N., Gitlin, L. N., Howard, R., Kales, H. C., Larson, E. B., Ritchie, K., Rockwood, K., Sampson, E. L., Samus, Q., Schneider, L. S., Selbæk, G., Teri, L. and Mukadam, N. (2017). Dementia prevention, intervention, and care. *The Lancet*, **390**.

- Mackenzie, J. (2006). Stigma and dementia: East European and South Asian family carers negotiating stigma in the UK. *Dementia*, **5**, 233–247.
- Maestre, G. E. (2012). Assessing Dementia in Resource-Poor Regions. *Current Neurology and Neuroscience Reports*, **12**, 511–19.
- Malik, M. A. (2015). Universal health coverage assessment Pakistan. Global Network for Health Equity.
- Milne, A. (2010). The ‘D’ word: Reflections on the relationship between stigma, discrimination and dementia. *Journal of Mental Health*, **19**, 227–33.
- Misra, A., Tandon, N., Ebrahim, S., Sattar, N., Alam, D., Shrivastava, U., Narayan, K. M. and Jafar, T. H. (2017). Diabetes, cardiovascular disease, and chronic kidney disease in South Asia: current status and future directions. *BMJ (Clinical research ed)*, **357**, j1420.
- Mukadam, N. and Livingston, G. (2012). Reducing the stigma associated with dementia: approaches and goals. *Aging Health*, **8**, 377–86.
- Mushi, D., Rongai, A., Paddick, S.-M., Dotchin, C., Mtuya, C. and Walker, R. (2014). Social representation and practices related to dementia in Hai District of Tanzania. *BMC Public Health*, **14**, 260.
- National Emergency Operation Centre (2017). National Emergency Action Plan for Polio Eradication.
- Nielsen, T. R. and Waldemar, G. (2016). Knowledge and perceptions of dementia and Alzheimer’s disease in four ethnic groups in Copenhagen, Denmark. *International Journal of Geriatric Psychiatry*, **31**, 222–30.

- Ott, A., Stolk, R. P., Van Harskamp, F., Pols, H. A. P., Hofman, A. and Breteler, M. M. B. (1999). Diabetes mellitus and the risk of dementia The Rotterdam Study. *Neurology*, **53**, 1937–1937.
- Pakistan Bureau of Statistics (2019). Population by Religion. Available online at <http://www.pbs.gov.pk/content/population-religion> [Accessed 7 January 2019].
- Patel, V. and Prince, M. (2001). Ageing and mental health in a developing country: who cares? Qualitative studies from Goa, India. *Psychological Medicine*, **31**, 29–38.
- Prince, M., Wimo, A., Guerchet, M., Ali, G.-C., Wu, Y.-T. and Prina, M. (2015). *World Alzheimer Report 2015: The Global Impact of Dementia*. Alzheimer's Disease International, London.
- Qadir, F., Gulzar, W., Haqqani, S. and Khalid, A. (2013). A pilot study examining the awareness, attitude, and burden of informal caregivers of patients with dementia. *Care Management Journals: Journal of Case Management; The Journal of Long Term Home Health Care*, **14**, 230–40.
- Randhawa, H., Jiwa, A. and Oremus, M. (2015). Identifying the components of clinical vignettes describing Alzheimer's disease or other dementias: a scoping review. *BMC Medical Informatics and Decision Making*, **15**, 54.
- Schoenberg, N. E. and Ravdal, H. (2000). Using vignettes in awareness and attitudinal research. *International Journal of Social Research Methodology*, **3**, 63–74.
- Smithson, J. (2008). Focus groups. *The Sage handbook of social research methods*, 357–369.
- Stewart, D. W. and Shamdasani, P. N. (2014). *Focus groups: Theory and practice*. Sage publications.

- Werner, P. (2003). Knowledge about symptoms of Alzheimer's disease: correlates and relationship to help-seeking behavior. *International Journal of Geriatric Psychiatry*, **18**, 1029–36.
- Whitmer, R. A., Sidney, S., Selby, J., Johnston, S. C. and Yaffe, K. (2005). Midlife cardiovascular risk factors and risk of dementia in late life. *Neurology*, **64**, 277–281.
- Willis, R., Zaidi, A., Balouch, S. and Farina, N. (2018). Experiences of People With Dementia in Pakistan: Help-Seeking, Understanding, Stigma, and Religion. *The Gerontologist*.
- World Health Organisation (2017a). Country Cooperation Strategy at a glance: Pakistan. World Health Organisation.
- World Health Organisation (2017b). *Dementia: a public health priority*. World Health Organization, Geneva, Switzerland.
- World Health Organisation (2014). Leading international Islamic scholars unite to protect children from polio paralysis. Available online at <http://www.emro.who.int/polio/polio-news/leading-international-islamic-scholars-unite-to-protect-children-from-polio-paralysis.html> [Accessed 24 January 2018].
- Zaidi, A. (2013). Global AgeWatch Index 2013: Purpose, Methodology and Results. University of Southampton, Southampton, UK.
- Zaidi, A., Stefanoni, S. and Khalil, H. (2018). Moving from the Margins: Promoting the Rights of Older Persons in Pakistan. Policy Brief. University of Southampton.
- Zaidi, A., Willis, R., Farina, N., Balouch, S., Jafri, H., Ahmed, I., Khan, Q. and Jaffri, R. (2019). Understanding, Beliefs and Treatment of Dementia in Pakistan: Final Report. London.

Figure 1: An example vignette of Mrs Shabnam (72 years old with mild dementia) adapted from La Fontaine et al., 2007.

Mrs Shabnam used to be very proud of her appearance and was actively involved with the family. She looked after her grandchildren happily and willingly and never missed an opportunity of visiting other members of her extended family.

However, things have changed since she was diagnosed with diabetes 6 months ago. A couple of months later, her family began noticing that she was becoming more changeable in her mood, becoming tearful at times for no apparent reason and taking less pride in her appearance. She has also now lost interest in providing care for her grandchildren and does not wish to make efforts to visit family and friends.

After her daughter-in-law persuaded her to attend her older grandson's wedding, it became apparent that she was having some difficulty in remembering the names of family members she had not seen for a while. During the wedding, her niece sat with her and began discussing the last family gathering, Mrs Shabnam's 70th birthday celebration. But she seemed confused and had difficulty remembering the gathering properly and who had attended. She found it much easier to join in a conversation about a wedding in Multan 40 years earlier. To the embarrassment of the Mrs Shabnam, she also found herself getting lost coming back from the bathroom at the venue.

Since the wedding, the family has been talking about the changes they are observing in her. Members of Mrs Shabnam's family are telling her daughter-in-law to take her to a local doctor; others are just saying there is nothing that can be done, it is just a part of the ageing process.

Table 1. Demographic details of participants across the four FGDs

	Male – Lahore	Female – Lahore	Male –Karachi	Female –Karachi
	(n=10)	(n=10)	(n=10)	(n=10)
	M (SD) [Range]	M (SD) [Range]	M (SD) [Range]	M (SD) [Range]
Age	37.7 (19.6) [17-68]	33.8 (11.0) [21-52]	33.7 (12.5) [22-64]	43.2 (7.8) [28-55]
Household Size	6.1 (1.7) [4-8]	7.1 (2.4) [4-12]	6.0 (1.6) [2-8]	6.9 (4.4) [2-15]
	N (valid %)	N (valid %)	N (valid %)	N (valid %)
Household Monthly Income				
(Rs)				
20,000 or less	1 (11.1%)	3 (37.5%)	1 (10.0%)	4 (40.0%)
20,001 to 40,000	4 (44.4%)	2 (25.0%)	8 (80.0%)	5 (50.0%)
40,001 to 60,000	1 (22.2%)	1 (12.5%)	0 (0.0%)	1 (10.0%)
60,001 to 80,000	1 (11.1%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
80,001 to 100,000	0 (0.0%)	0 (0.0%)	1 (10.0%)	0 (0.0%)
100,001 or more	2 (22.2%)	2 (25.0%)	0 (0.0%)	0 (0.0%)
Highest Education				
Graduate degree or higher	1 (11.1%)	3 (37.5%)	0 (0.0%)	2 (20.0%)
Undergraduate degree	3 (33.3%)	1 (12.5%)	0 (0.0%)	0 (0.0%)
A levels or FSc	3 (33.3%)	1 (12.5%)	5 (50.0%)	0 (0.0%)
O level or matriculation	0 (0.0%)	0 (0.0%)	3 (30.0%)	2 (20.0%)
HSSC	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
SSC	1 (11.1%)	2 (25.0%)	1 (10.0%)	2 (20.0%)
Primary or less	1 (11.1%)	1 (12.5%)	0 (0.0%)	4 (40.0%)
Other	0 (0.0%)	0 (0.0%)	1 (10.0%)	0 (0.0%)

Professional Status

Retired	2 (22.2%)	0 (0.0%)	1 (10.0%)	0 (0.0%)
Unemployed	2 (22.2%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Employed	5 (55.5%)	4 (50.0%)	9 (90.0%)	4 (20.0%)
Homemaker	0 (0.0%)	4 (50.0%)	0 (0.0%)	6 (60.0%)

Marital Status

Never Married	2 (20.0%)	3 (37.5%)	3 (30.0%)	0 (0.0%)
Currently Married	7 (70.0%)	5 (62.5%)	6 (60.0%)	8 (80.0%)
Widowed	0 (0.0%)	0 (0.0%)	1 (10.0%)	2 (20.0%)

Home Ownership

Owned	3 (33.3%)	7 (87.5%)	8 (80.0%)	7 (70.0%)
Rented	2 (22.2%)	1 (12.5%)	2 (20.0%)	2 (20.0%)
State	2 (22.2%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Family	2 (22.2%)	0 (0.0%)	0 (0.0%)	1 (10.0%)

Rs = Pakistani Rupees, SD = Standard Deviation, SSC = Secondary School Certificate , HSSC = Higher Secondary School Certificate, FSc = Faculty of Science.